

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

Form Approved

OMB No. xxxx-xxxx
Exp.Date: xx/xx/xxxx

AMERICAN ACADEMY OF PEDIATRICS PRE-TRAINING EVALUATION SURVEY

The public reporting burden of this collection of information is estimated to average 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to - CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333 ATTN: PRA (xxxx-xxxx)

Thank you for your interest in fetal alcohol spectrum disorders (FASD). We would like to invite you to complete a pre-training evaluation survey. We appreciate your willingness to help us evaluate the effectiveness of the training and its impact on your practice and care of children with FASDs.

This survey will take approximately 15 minutes to complete. Your responses will be kept secure and no individually identifying information will be included. Risks to participating in this survey are minimal and include the risk of your information becoming known to individuals outside the American Academy of Pediatrics (AAP). This project is being conducted with support from the Centers for Disease Control and Prevention (CoAg# OT18-1802). We plan to share findings with CDC in de-identified, aggregate form.

Your participation in this survey is voluntary. You may decline to answer any question and you have the right to stop the survey at any time.

Please submit questions to the project partners at PEHDIC@aap.org.

UNIQUE IDENTIFIER INFORMATION (to help us match your pre- and post-training responses)

Today's date: ___ ___ / ___ ___ / ___ ___

1. First 2 letters of your mother's maiden name ___ ___
2. Month of your birthday ___ ___
3. Last 2 digits of your social security number ___ ___
4. State in which you practice ___ ___

KNOWLEDGE QUESTIONS

5. Which of the following could indicate that a child may have been exposed to alcohol prenatally?
(Check all that apply)

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

- A. Growth deficiencies
- B. Thrombocytopenia
- C. Cognitive/developmental deficiencies or discrepancies
- D. Executive function deficits
- E. Delays in gross/fine motor function
- F. Problems with self-regulation/self-soothing
- G. Delayed adaptive skills
- H. Hypothyroidism
- I. Macrocephaly

6. Which of the following statements is a rationale for making a diagnosis of an FASD? A diagnosis of FAS/an FASD will: (Check all that apply)

- A. Help facilitate understanding of the child's strengths and challenges as it relates to neurobehavioral functioning.
- B. Helps provide the framework for the parents and teachers to provide the environment necessary for the child to succeed.
- C. Help provide the developmental and educational interventions that could lead to better outcomes.
- D. Help children and families avoid bias.
- E. Help differentiate between an FASD and other causes of developmental delays, which may warrant different learning/treatment approaches.

7. Which of the following approaches can be used to manage and treat FASDs? (Check all that apply)

- A. A combination of special education, vocational programs, and tutors.
- B. Medication for treating specific symptoms.
- C. Behavioral and developmental evaluation and therapy.
- D. Interventions that include parent-child interaction in a structured environment.
- E. Trial on alternative diets such as limiting sugar and carbohydrate intake or diets rich in calcium.

8. A child with no physical stigmata of FAS has evidence of structural brain abnormalities and functional neurocognitive disabilities, which manifest as problems with behavior, adaptive skills, and self-regulation. Which of the following is not an appropriate plan of action? (check all that apply)

- A. Collect a comprehensive history of prenatal exposures, including tobacco, alcohol, illicit drugs or other medications.
- B. Evaluate for possible genetic and environmental etiologies.
- C. Consider an FASD diagnosis such as ND-PAE in your differential diagnosis.
- D. Provide anticipatory guidance to parents/caregivers while reassuring them that since the child has no facial features of fetal alcohol syndrome, the child's problems must be related to another disorder.
- E. Educate the parent about impairments seen in children with FASD so they can better understand and respond to their child's behavioral challenges.

9. Complete the sentence by selecting all answers that are applicable.

It is important to obtain the history of prenatal alcohol exposure and identify a patient with an FASD even if a child is already in the school-age years because children with prenatal alcohol exposure:

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

- A. Can have behavioral problems that do not respond to traditional parenting or behavioral intervention strategies.
- B. May need a different approach to learning (may need an individualized education plan in the school setting).
- C. May have social skill deficits that need to be addressed with close supervision and guidance and support in peer and adult interactions.
- D. May not have discernible problems in expressive language which can mask disabilities in auditory processing, receptive communication, and social pragmatic use of speech as well as other hidden disabilities.
- E. Have impairments and disabilities that often do not improve until they reach adulthood.

OPINION QUESTIONS

10. Which of the following two statements below best corresponds with your personal viewpoint?
Please check only ONE.

- Occasional consumption of one standard alcoholic drink per day or less (i.e., 1.5 oz. hard liquor, 12 oz. of beer or 5 oz. of wine) during pregnancy is not harmful to the mother or the fetus.
- Pregnant women or women who are trying to become pregnant should completely abstain from consuming alcohol.

11. To what extent do you agree with the following statements? (Mark one response per row)

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
a. Concern about mothers'/parents' response to screening for prenatal alcohol exposure is a barrier to screening.	1	2	3	4	5
b. Diagnosis of one of the FASDs may confer a negative stigma to a child and/or his or her family	1	2	3	4	5
c. Diagnosis of one of the FASDs only needs to be considered for certain populations	1	2	3	4	5

12. To what extent do you agree with the following statements about alcohol consumption during pregnancy? (Mark one response per row)

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

Alcohol consumption during pregnancy...	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
a. Is more prevalent in women with higher incomes	1	2	3	4	5
b. Is more prevalent in women with higher levels of education	1	2	3	4	5
c. Does not vary between ethnic or racial groups	1	2	3	4	5

13. The following questions are regarding biological mothers of children with Fetal Alcohol Spectrum Disorders (FASDs). Please indicate your answer to each item on the corresponding 9-point scale.

	Very								Not at all
a. How similar do you think a women who consumes alcohol while pregnant is compared to everyone else in the general population?	1	2	3	4	5	6	7	8	9
b. How good do you think a biological mother of children with FASD is compared to everyone else in the general population?	1	2	3	4	5	6	7	8	9
c. How respected do you think a biological mother of children with FASD is compared to everyone else in the general population?	1	2	3	4	5	6	7	8	9
d. How responsible do you think a biological mother of children with FASD is for her child's condition?	1	2	3	4	5	6	7	8	9
e. How blamed do you think is a biological mother of children with FASD for her child's condition?	1	2	3	4	5	6	7	8	9

PRACTICE QUESTIONS

If any of the following screening, diagnostic or referral items do not apply to you in your current position, please circle "N/A" for each item that is not applicable.

14. How often do you do the following? (Mark one number per row)

	N/A	Never	Rarely	Sometimes	Usually	Always
a. Inquire routinely about prenatal exposure to alcohol	0	1	2	3	4	5
b. Identify patient as someone who	0	1	2	3	4	5

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

	N/A	Never	Rarely	Sometimes	Usually	Always
may have one of the FASDs						
c. Diagnose patient as someone who may have one of the FASDs	0	1	2	3	4	5
d. Refer patient for diagnosis and/or treatment services	0	1	2	3	4	5

15. How confident are you in your skills to do the following? (Mark one number per row)

	N/A	Not at all Confident in my Skills	A Little Confident in my Skills	Moderately Confident in my Skills	Confident in my Skills	Completely Confident in my skills
a. Inquire about potential prenatal alcohol exposure for pediatric patients	0	1	2	3	4	5
b. Identify persons with possible FAS or other prenatal alcohol-related disorders	0	1	2	3	4	5
c. Diagnose persons with possible FAS or other prenatal alcohol-related disorders	0	1	2	3	4	5

16. How willing are you to do the following? (Mark one response per row)

	N/A	Not at all Willing	A little Willing	Moderately Willing	Willing	Completely Willing
a. Inquire about potential prenatal alcohol exposure for pediatric patients	0	1	2	3	4	5
b. Identify persons with possible FAS or other prenatal alcohol-related disorders	0	1	2	3	4	5
c. Diagnose persons with possible FAS or other prenatal alcohol-related disorders	0	1	2	3	4	5

17. During the past six months, did you diagnose any children with fetal alcohol syndrome (FAS) or one of the fetal alcohol spectrum disorders (FASDs)?

N/A [0] Yes [1] No [2]

If YES, please specify which diagnostic schema (if any) you used to support your diagnosis: (Mark all that apply)

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

- Institute of Medicine criteria
- American Academy of Pediatrics algorithm and/or toolkit
- Seattle 4-Digit Diagnostic Code (University of Washington)
- Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
- Other schema (please specify) _____
- I did not use any particular schema

18. During the past six months, did you refer any children for FASD assessment?

- N/A [0] Yes [1] No [2]

GENERAL

19. Please feel free to comment on your response to any of the questions in this survey.

Please take a moment to tell us about yourself:	
<p>How would you describe your gender identity?</p> <p><input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender <input type="checkbox"/> Prefer not to answer</p> <p>Are you Hispanic or Latinx?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes (includes: Mexican, Mexican American, Chicano, Puerto Rican, Cuban, or other Hispanic or Latinx)</p> <p>With what racial or cultural group(s) do you identify yourself? (Mark all that apply)</p> <p><input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian or other Pacific Islander</p>	<p>What year did you complete or will you complete your training:</p> <p>_____</p> <p>Are you, or will you be, a:</p> <p><input type="checkbox"/> Primary Care Pediatrician <input type="checkbox"/> Developmental/Behavioral Pediatrician <input type="checkbox"/> Geneticist <input type="checkbox"/> Other Pediatric Sub-specialty Specify: _____</p> <p><input type="checkbox"/> Family Physician <input type="checkbox"/> Other (specify): _____</p> <p>Please indicate your primary employment site setting, that is, the setting where you spend most of your time. Mark only ONE response.</p> <p><input type="checkbox"/> Self-employed solo practice <input type="checkbox"/> Two physician practice <input type="checkbox"/> Pediatric group practice, 3-10 pediatricians <input type="checkbox"/> Pediatric group practice, >10 pediatricians <input type="checkbox"/> Multispecialty group practice <input type="checkbox"/> Health maintenance organization (staff model) <input type="checkbox"/> Medical school or parent university</p>

Improving Continuity of Care for Children and Families Affected by Prenatal Alcohol Exposure

<input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> White	<input type="checkbox"/> Non-profit community health center <input type="checkbox"/> Non-government hospital or clinic <input type="checkbox"/> City/county/state government hospital or clinic <input type="checkbox"/> US government hospital or clinic <input type="checkbox"/> Other: _____ Please describe the community in which your primary practice/position is located? <input type="checkbox"/> Urban, inner city <input type="checkbox"/> Urban, not inner city <input type="checkbox"/> Suburban <input type="checkbox"/> Rural
---	--

Thank you for taking the time to answer these questions!